

Medicine in Perspective

Ethical Crises and Cultural Differences

AFAF IBRAHIM MELEIS, PhD, and ALBERT R. JONSEN, PhD, San Francisco

Generalizations about patients without careful attention to their cultural background, their values and norms could lead to a number of ethical crises. The informed consent, disclosure of diagnosis and prognosis, and discussions of termination of treatment are reflections of Western cultural values. They represent respect for autonomy of clients and respect for openness in communications. For patients from other cultures such practices have different meanings that may violate their own values. The result of such conflict in practices and meanings can render the relationship between patients and health care personnel difficult at best and distrustful at worst.

Contemporary medical ethics strongly endorse certain practices such as informed consent, disclosure of diagnosis and prognosis, and termination of treatment under certain conditions of terminal illness. These practices are endorsed, in part, because they reflect certain values widely held in Western culture: the autonomy of the individual person, the imperatives favoring truthfulness and open communication, and the realistic assessment of the efficacy of medical care.¹ However, American physicians who accept these practices and the values they represent may encounter patients from cultural backgrounds where the practices are not meaningful. Physicians, acting in good conscience, may find themselves in difficult situations when such patients and their families react negatively or paradoxically to these practices. An example of such a difficult situation is reported and the case analyzed in light of the cultural expectations of the patients.

The patient presented in this case is an Arab, coming from a culture whose representatives, though not seen as frequently in American medical care as Hispanics and Asians, are appearing more and more frequently. Although the cultural values described in this article are proper to Arabs, the lesson is universal: it is necessary, from both an ethical and a practical viewpoint, to comprehend the values and beliefs of patients from cultures quite different from our own.

Report of a Case

Mr Ahmed, a 28-year-old man of Egyptian birth, had come to the United States six months earlier to join his mother, two brothers and one sister. He came

to the emergency room of a university hospital with a severely swollen and inflamed neck. He was cachectic and dyspneic. Swollen, rubbery lymph nodes were noted in the neck. He spoke English haltingly, but did communicate with his brother's help that he had been told several years earlier that he had cancer. He was treated in several foreign hospitals, but had not seen a doctor since his arrival in the United States. A presumptive diagnosis of Hodgkin's disease was made, and he was admitted for treatment of cellulitis and edema of the neck as well as for evaluation for chemotherapy. His family accompanied him and remained around the clock in the visitors' room. The mother spoke no English; the brothers and the sister spoke it adequately but not fluently.

Informed Consent

Mr Ahmed's medical history was not well documented. When he and his family were questioned about personal or family health history and business or social status, they reacted with suspicion. Providers of care did not make any effort to clarify the relationship between the "intrusive" questions and the medical problem. In some cultures, the fewer the number of questions asked, the less intrusive they are and therefore the better the health care.² This is one of the values that Arab-Americans hold and is certainly not a value of the Western health care system. As a result, many questions went unanswered.

Mr Ahmed had been treated in hospitals in Greece and in England before coming to the United States. Clinical examination showed signs consistent with

Refer to: Meleis AI, Jonsen AR: Ethical crises and cultural differences (Medicine in Perspective). West J Med 1983 Jun; 138:889-893.

Dr Meleis is Professor, Department of Mental Health and Community Nursing, School of Nursing, and Dr Jonsen is Professor of Ethics in Medicine, School of Medicine, University of California, San Francisco.

Reprint requests to Afaf I. Meleis, PhD, Professor of Nursing, Department of Mental Health and Community Nursing, University of California, San Francisco, School of Nursing, N5054, San Francisco, CA 94143.

Hodgkin's disease, but there was no reliable information about the stage of the disease. Mr Ahmed had said he had been sick for about three years and that he had been treated with x-rays and with drugs. Node and liver biopsy studies seemed appropriate and were recommended to him. The family seemed to agree verbally with the recommendations. However, when the resident asked Mr Ahmed to sign the consent form, he refused. His mother and two brothers, who were in the room at the time, strongly supported him and seemed very angry. The resident could not understand the reason for the refusal. Mr Ahmed simply refused to explain, and the language differences presented a barrier to clearer communication.

Discussion

Anglo-American law has long required consent for surgical procedures. Except in emergencies, a doctor who operates without the consent of the patient can be charged with battery. In recent years, the doctrine of consent has been elaborated into a doctrine of *informed* consent: the physician must inform the patient of the nature of the illness, of the benefits and risks of treatment, and of alternatives. The patient may assess this information and accept or refuse the doctor's recommendations. The ethical basis for the doctrine of informed consent is respect for the autonomy of the patient—that is, acknowledgment by the doctor (and all others) that the patient is a person with the right to control his or her own life. The value of autonomy has deep roots in Western culture and has been an important concept in Western philosophy. In addition, autonomy has been associated with the ability to make a rational decision based upon knowledge and with the opportunity to choose among several options. Thus, even though the legal and ethical doctrine of informed consent has only recently become prominent in medical practice, it has a firm place in the Western value system.³⁻⁵

It has become common to request consent and, for many procedures, to ask the patient to sign a consent form. Consent in writing has a different symbolic meaning to an Arab in his homeland, and such meaning becomes more complex when an Arab interacts with foreign (to him) health care workers. Once Arabs give their verbal agreement to a contract, they consider it binding and equal to their written agreement. To press them further to a written agreement only suggests mistrust of their verbal contract. The legal validity of such verbal contract is not the essential issue; personal honor is at stake and is challenged when someone is pressed to give a written consent after a verbal consent is already given. Therefore, this point causes many frustrations to health care professionals when they ask or demand a written consent for every procedure carried out on patients, although it is a plausible explanation for the seeming paradox on the part of an Arab patient toward verbal versus written consent.

Even the *request* for consent creates a problem. Arab-Americans have respect for authority figures.

Such figures represent expertise based on experience and education. This means speaking knowingly about the matter at hand, and it also means making decisions for others and being accountable for such decisions. Therefore, the concept of options, alternatives and taking responsibility for one's actions that is unique to the Western hemisphere is foreign to Arab-American patients. For an Arab-American, taking responsibility for one's decisions is not accomplished through a mere signature on a consent form; it can only be accomplished when a person has acquired the education and experience that allows him to make informed decisions and give an informed consent.

It is not only the issue of informed written consent that is a problem for Arab-American patients, but also the manner in which such consent is requested. Arabs tend to want to chat around a theme and to take their time before the crux of the interaction is approached.⁶ They are not too eager to get down to business and prefer to get to know each other personally and about each other's family before the business transaction is handled. The informed consent process is professional, technical and succinct; it appears highly inhuman to the Arab eye. This becomes even more complicated when a patient's condition is critical. Not only do the patient and the family expect to receive humanistic care, they expect all those who surround them to be emotional and subjective. The last thing they would expect is a cold, calculated transaction. Health care professionals who ask for written consent during crises are perceived as cold and calculating, and therefore are to be mistrusted. On the other hand, health care professionals will label such patients as uncooperative and noncompliant, and they readily consider them "difficult patients."

The perception of the efficient but mechanical professional attitude is most certainly not confined to the Arab-American patient's way of thinking. Patients from other cultures, such as Latinos, have expressed similar views.⁷

Disclosure of Information

On the second hospital day, Mr Ahmed was sipping soup and choked. As a result of difficulty in placing the tracheotomy tube, he suffered five to seven minutes of anoxia. Use of a respirator was begun and the patient remained in deep coma, although his neurological status did not meet brain death criteria.⁸ After Mr Ahmed had aspirated and the neurology consultants had confirmed anoxic encephalopathy with poor prognosis for recovery, the family was approached by the resident and an intern who spoke some Arabic. They explained the situation as fully and as frankly as they could under the circumstances of limited communication. The interview was disrupted by extreme manifestations of grief by the mother and by the family's attention to her rather than to the doctors. However, the physicians felt they had communicated the essential information: Mr Ahmed had suffered serious brain damage and would, in all probability, not recover con-

sciousness although he might continue to live, with or without respiratory support. They did not feel they could bring up the issue of termination of life support under the circumstances. However, in subsequent days they did so and were met with anger and outrage.

In Western culture, direct and honest communication of facts about a situation is highly valued. Deceit is considered reprehensible, and circuitous as well as metaphorical modes of communication are not encouraged. Within this general approbation for direct communication, there has long been a debate among physicians about how frankly fateful information should be imparted to patients. In recent years, commentators on this issue have come to favor full and truthful disclosure. They argue that not only is the truth demanded by ethical principle, but there is no evidence patients are harmed by it and considerable experience indicates that they are helped by knowing their diagnosis. Thus the physicians in this case acted in accord with values that are widely supported by their culture and, in recent years, by the profession.

Arabs, while valuing open communication and truth, view differently the circumstances involving crises, disaster and, most particularly, those related to terminal illness and impending death. Other cultures hold such values as well.² To confront a patient with his grave diagnosis and poor prognosis is not only a tactless act but an unforgivable one, one which in fact might bring disaster to that person. Such a confrontation is not congruent with the rules that govern communication of Arab Moslems. Hope helps a patient mobilize his own resources to cope with the illness, even if such hope is false by Western standards. As long as the patient has faith in Allah and his power, hope is never false. To utter the words related to the grave situation in front of the patient or his closest kin—especially if the kin is female—as we invariably do in the West because of our belief that patients are entitled to the truth, only renders the patient hopeless and ready to give up. Worse yet, to do so suggests that the health professional has given up on the patient and therefore will not continue to handle the case with the same care and expertise as before.

Members of the family are expected to act as a clearinghouse of information, especially information related to grave diagnoses.⁹ Health care professionals should couch the truth with unfailing hope and protect the patient by communicating the truth to other persons in the family who have been identified as spokespersons, ones who are looked up to by family members as the advisors and counselors (men before women and older before younger).

This refusal to hear the truth might be considered by Western interpreters to be denial. The Eastern mind has a different interpretation. Only God knows how poor a prognosis is; only God knows whether we should give up or not. Our hope should never wane or else God's help will not be forthcoming. How could the patient's family trust health professionals who have declared a "no hope," a "hands off" or a "wait for

death" policy? Arabs, whether Christian or Moslem, value hope until the bitter end. Hope is only shattered when the physician—representing the power of Western medicine—declares the prognosis of impending death. This declaration can engender deep mistrust for the physician, and this mistrust is conditioned by social values, religion and the reverence accorded Western medicine.

Arab-Americans value Western medicine highly. Western medicine epitomizes expertise, science and technology. Patients who die in the Arab world die because it is the will of Allah, but also because of the inadequacy of equipment, medications and the like. Even though Arab-Americans continue to speak of the *evil eye* and of hot and cold as contributing to disease, Western medicine is sought and practiced assiduously. It is believed that more intrusive procedures are more effective: intramuscular injections are preferred to pills, and intravenous treatment to intramuscular.¹⁰ In spite of this respect for medicine, however, medical preparation for impending events such as birth and death is diametrically opposed to an Arab's values and beliefs. These should be left in the hands of God until they actually occur. To do otherwise is to outguess God and could bring eventual disaster to the family.

An Arab's extreme reluctance to speak of death, to anticipate and prepare for it, should not be confused with his acceptance of its inevitability. An Arab does not deny the reality of death,⁹ but Arabic beliefs forbid speaking of it or, worse yet, expecting it at a specific time proclaimed by another mortal. If, as it sometimes happens, it is necessary to speak of death,

two phenomena occur; God is mentioned in one form or another, and a euphemism is substituted for the word "death." Often the term used is an ingenious condensation of the two. For example, the dead person is spoken of as "One Whom God has Claimed as a Debt" (Mutawaffi), as "One Forgiven" (Marhoom), or as "One Who Passed to God's Mercy" (Maghfur Lahu); or he is referred to as the one "Lost" (Al-Faqeed), or the "Precious Lost" (Al-Faqeed Al-Ghali), after which God's forgiveness is invoked by a second phrase.¹¹

Under the very unique circumstances when death has to be spoken of in futuristic terms, it is never connected with a particular person and, even then, it has its euphemisms, such as "Al-Maktoob" or "Al-Muggadder" ("what is willed" or the "Destined"), then evil is quickly denounced by saying "Baad-Al-Shar."

This cultural background rendered Mr Ahmed's family suspicious and distrustful of the intentions of the health care personnel. Matters became worse when the question of termination of life support was introduced.

Termination of Life Support

The attending physician and the house officers reached the conclusion that Mr Ahmed had suffered irreversible brain damage. In addition, they suspected he was also suffering from a lethal disease in an advanced stage. It was their unanimous opinion that respiratory support should be terminated. Although Mr Ahmed was not "brain dead" because he still had brain stem functions, the physicians believed his recovery to

"conscious and sapient life" was beyond the realm of possibility. They consulted with the medical ethics committee of the hospital and with legal counsel and were supported in their opinion that termination of life support was ethical and in accord with leading legal opinion. Thus, they decided to recommend this to Mr Ahmed's family. They were also aware they did not need the family's permission to act on their medical decision, but they did wish to have the family's understanding and agreement.

In following this course, the physicians were acting in conformity with a growing consensus of medical, legal and ethical opinion. The technology of critical care medicine is not only capable of supporting seriously ill patients during crucial episodes, it is also able to support organic function when little or no therapeutic potential remains. The limitation of such support to those situations where some benefits are still possible or probable is broadly, if not unanimously, approved by physicians and the general population. "Being kept alive as a vegetable" is not, for most persons, a desirable goal.

Within this general consensus, many debates have taken place about what is permitted and what is forbidden. An extensive literature about termination of medical intervention, about active and passive euthanasia, about "order not to resuscitate" has appeared.¹² Fifteen states have passed "brain death" legislation that permits physicians to terminate life support when evidence supports the diagnosis of total and irreversible cessation of brain function, including the brain stem.⁸ Ten states have passed legislation giving legal status to those documents, sometimes called "living wills," in which persons in good health can direct their physicians to cease supporting interventions when hope of recovery is lost.^{13,14} A number of important legal opinions, starting with the Karen Ann Quinlan case, have addressed the problem. While these differ in many respects, they move in the direction of giving legal sanction to discontinuing life support, or not initiating medical intervention, when attainment of significant medical goals appears unlikely.¹⁵

The health care personnel had already violated the values and beliefs of Mr Ahmed's family on several accounts. Many questions were asked about such personal things as the patient's and the family's health and social status, questions which were regarded suspiciously because the nature of the relationship between the medical problem and the personal questions was not apparent. A grave prognosis was announced, even before the choking incident, and Western medicine failed in taking care of the consequence of the choking. The last straw for the family, who were deeply religious and who espoused an Arab value and belief system, was to be confronted by questions related to "termination of life support," a discussion that managed to heighten suspicion and mistrust and that prompted the family to take turns around the clock watching their beloved member to halt any attempts on the health care personnel's part to terminate life support.

Mr Amed's two brothers and sister took leaves of absence from their jobs to be with the patient and their mother, who was a constant vocal and angry companion. They raised many questions and made the staff very uncomfortable. The family's behavior, explained within the trust/nontrust context, has even more meaning when examined in relation to a culture's methods of coping with stress.

Coping Styles of Arabs

There are several predominant styles of coping with stressful events: problem solving, information seeking, direct action, inhibition of action and intrapsychic process.^{16,17} A person uses one or more, depending on his or her appraisal of the stressful event as a threat or a challenge.¹⁸

An Arab's predominant coping style is "turning to others" for help and advice.¹⁹ In doing so, the need for others' help is not directly communicated; rather, it is understood and acted upon without being verbally articulated. The expected help must be offered with persistence and force and, whether the seeker acknowledges the need or not, the offer must be repeated. This creates one of the major issues encountered in caring for Arab clients. Their beds are invariably surrounded by relatives and friends. The health care providers are amazed at the number of persons who are constantly in the way of the hospital routine and who seem to interfere with the kind of care the health care personnel prefer to give.

Such behavior has a different meaning within the Arab cultural context. Arabs have very high affiliation needs even when not in crisis or under stress. This is manifested in their social patterns and preference for occupations that involve constant human interaction and contact. When under stress of illness, such needs are intensified; the patients must be constantly bathed in care and attention, and the extended and nuclear families and friends must become exorbitant in manifesting such care. To show their concern for the patient, family members and friends are expected to manifest two sets of behavior. They must be around the patient as much of the time as possible, and they must become very demanding of health care personnel. Such demanding demeanor portrays caring for the patient as well as respect for the health care system's omnipotence in "curing" and handling the client's problems. It is a manifestation of total resignation to simply leave the matter to God and not to question the health care system. Such behavior is misinterpreted by health care professionals and leads them to reject and avoid Arab patients.

In this case, health care providers attempted to improve the situation by doing what might appear, to Western eyes, quite an appropriate thing: they called in a religious advisor. A Moslem sheikh was summoned to comfort the family. The very sight of the sheikh in the hospital room of the comatose patient heightened the family's and friends' mistrust of the professionals caring for the patient. To them, the well-meaning inten-

tion of the medical personnel was symbolically analogous to bringing in a Catholic priest to perform the last rites and to comfort the family.

As discussed above, an Arab Moslem family (or an Arab Christian family, for that matter) is not expected to plan for death, or to ever give up hope, even under the gravest of circumstances. To do either is bound to defy God's will and might bring about a worse prognosis at best and a premature death at worst. The sheikh's appearance, therefore, contradicted their belief. One might ask, "Why did a Moslem sheikh agree to the mission?" The Moslem sheikh was a non-Arab; therefore it is possible that there were conflicting cultural values that prompted such a response. Possibly he believed the request had been made by a more Westernized Arab-American Moslem. To be called to help and to respond by questioning the wisdom of such help is not congruent with the Islamic laws guiding a Moslem sheikh.

The damage from this well-intended act was profound. The family of the dying, comatose patient perceived it as a sign of hopelessness on the part of the health care team. They became extremely fearful that, in spite of their pleas and their hope, the beloved patient would now be willfully left to die and no measures would be taken to save him, all of which was against their wishes. Suspicion increased; cooperation decreased.

Conclusion

Generalizations about any culture or people must be viewed critically. Within broad cultural communities there are almost infinite differences; persons from any culture are not stereotypes but unique. Still, whether Arab patients are Saudis, Kuwaitis or Egyptians, whether they are city or country reared and whether they are Christians or Moslems, there is a core of Arabism. Their cultural perspective can encounter profound difficulties when it meets the values of the Western system of health care. There are differences in values, in perceptions, in expectations, and in style of expression and behavior. This article has described some of these that go beyond mere difficulties in linguistic communication; they touch the most serious ethical responsibilities of health care providers, as we perceive these responsibilities. The experience described above involved the obligation of obtaining permission to treat and deciding to terminate treatment. The performance of these responsibilities was rendered extremely difficult by the inability on both sides to understand how actions and statements were perceived within the cultural context.

There are no simple solutions to this problem. It occurs whenever persons from a culture different from the Western one, in which most of our professionals have been raised, enter the health care system in any number. Professionals cannot, of course, become instant anthropologists. They cannot master the nuances of behavior formed by a very different type of education and rearing. They may be able, with effort, to read a

bit about their clients' mores and psychology; they may be able to learn a bit of their language. They can, more often, call for help in interpreting behavior. This is perhaps the most frequent failure of Western professionals. They have supreme confidence in their ability to manage a difficult situation. They rarely consider seeking consultants, who may not be medical professionals, to help them assess and solve difficulties in language, in life-style and in value preferences. However, institutions that serve patients from different cultures have an obligation to identify persons who can provide such help. They should be invited to educate the staff and should be called upon for consultation. For example, though the situation described in this case would be a difficult one to handle, no matter which culture a person belonged to, if the health care personnel had been aware of the cultural mores of the Arab family they could have prevented several major issues described in this discussion. More significantly, they would have avoided the mistrust that evolved from direct disclosure of a grave prognosis and from misinterpretation of the meaning of the consent procedures. They could have cast the numerous personal questions with a meaning related to benefits to the patient rather than to the hospital, as is often perceived by patients.

Finally, health care professionals should be sensitive to and care about the deeply felt values of their patients. These values may appear absurd or irrational to the Western eye, particularly eyes that see the world in scientific and technical images. Yet if we have learned anything from sociology and anthropology, it is that the values and behaviors of all cultures, viewed with understanding and sympathy, have profound meaning for survival and human well-being.

REFERENCES

1. Beauchamp TL, Childress JF: *Principles of Biomedical Ethics*. New York, Oxford University Press, 1979
2. Kleinman A: *Patients and Healers in the Context of Culture*. Berkeley, University of California Press, 1980
3. Annas GJ: Informed consent. *Annu Rev Med* 1978; 29:9-14
4. Barber B: *Informed Consent in Medical Therapy and Research*. New Brunswick, NJ, Rutgers University Press, 1980
5. Donagan A: Informed consent in therapy and experimentation. *J Med Phil* 1977; 2:307-329
6. Hall E: *The Hidden Dimension*. New York, Doubleday Anchor Press, 1969
7. Clark M: *Health in the Mexican Culture*, 2nd Ed. Berkeley, University of California Press, 1970
8. Black PM: Brain death I-II. *N Engl J Med* 1978 Aug 17 & Aug 24; 299:388-344, 393-401
9. Wigle LD: An Arab Muslim community in Michigan. In Aswad B (Ed): *Arabic Speaking Communities in American Cities*. New York, Center for Migration Studies, 1974
10. Meleis AI: The health care system of Kuwait: The social paradoxes. *Soc Sci Med* 1979; 13A:743-749
11. Racy J: Death in an Arab culture. *Ann NY Acad Sci* 1969; 164: 871-880
12. Veatch R: *Death, Dying and the Biological Revolution*. New Haven, Yale University Press, 1976
13. Bok S: Personal directions for care at the end of life. *N Engl J Med* 1976 Aug 12; 295:367-369
14. Veatch RM: Death and dying: The legislative options. *Hastings Cent Rep* 1977 Oct; 7:5-8
15. Robertson JA: Legal norms and procedures for withholding care from incompetent patients. In Abernethy V (Ed): *Frontiers in Medical Ethics*. Cambridge, Ballinger Publishing, 1980
16. Lazarus R: *Psychological Stress and the Coping Process*. New York, McGraw-Hill, 1966
17. Cohen F, Lazarus RS: Coping with the stresses of illness. In Stone GC, et al (Eds): *Health Psychology—A Handbook: Theories, Applications and Challenges of a Psychological Approach to Health Care Systems*. San Francisco, Jossey-Bass, 1979, pp 219-254
18. Lazarus R, Launier R: Stress-related transactions between person and environment. In Pervin L, Lewis M (Eds): *Internal and External Determinants of Behavior*. New York, Plenum, 1979
19. Abu-Laban B: *An Olive Branch on the Family Tree: The Arabs in Canada*. Toronto, McLelland & Stewart, 1980